

Foundation Quarterly

**NFL's Iman
Marshall shares
his family story**

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Our Caregiver Issue

**+ In your
Community,
News Briefs,
Wellness Tips**

Welcome

to the **Spring issue of Foundation Quarterly!**

In this issue, we wanted to honor the countless parents, families and caregivers in our community who have embarked on the epilepsy journey with their loved ones. The pandemic has taught us many things; one of which is how essential caregiving and caring for someone is to the fabric of our society. That is especially true for people in the epilepsy community.

While caregivers give of their time willingly and lovingly, caring for someone with a chronic condition can be overwhelming and at times, stressful. Yet, these caregivers play a vital role in the physical and emotional well-being of their loved ones. That is why in this issue of the Foundation Quarterly we are sharing stories that show the incredible compassion and strength of people who care for others with epilepsy.

Our cover story is Iman Lewis Marshall; although everyone knows Iman as the cornerback for the Baltimore Ravens, not a lot of people know of his little brother's epilepsy journey. Yasa's personal essay chronicles her journey accepting and embracing her fiancé's epilepsy. And then there is Kim, a mom juggling virtual learning and four children, two of whom have a genetic form of epilepsy. Finally, Nikki's story highlights her ongoing efforts to pass legislation to effect change for her 12-year-old son who lives with epilepsy.

Whether it is dealing with the day-to-day demands of making sure medications are taken on time, administering first aid during seizures, going to appointments with healthcare providers, or engaging in advocacy, these caregivers give it their all to support their loved ones in this journey.

I hope you will enjoy reading these amazing journeys and join me in sharing their stories.



A handwritten signature in black ink that reads "Laura S. Thrall".

Laura Thrall
President & CEO

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Photo courtesy of the Nye Family

Balancing Virtual Learning and Two Children with a Rare Epilepsy

When Kim Nye started her nonprofit organization, TESS Research Foundation, there was not a lot of information about the rare type of epilepsy that affected two out of her four children. Her 17-year-old daughter, Tessa, and her 7-year-old son, Colton, both have a rare form of genetic epilepsy caused by mutations in the SLC13A5 gene. Shortly after her birth, Tessa began having status seizures, a common occurrence in babies with SLC13A5 Epilepsy. Her seizures were difficult to control with seizure medications, and the family found themselves in the emergency room often, trying to stop her life-threatening seizures. Tessa also experienced developmental delays in motor control, speech, and cognition.

“We spent 10 years looking for the cause of her seizures,” said Kim. “Yet, despite having so many seizures, doctors couldn’t figure out what was going on. And it did not help that her brain MRI and even her EEG looked normal in between seizures. It was a mystery.”

At that time, there were not a lot of genes that were associated with epilepsy, so the Nye family decided to have more children and along came two more girls, both of whom are healthy. Seven years ago, Kim and her husband decided to try again for another child and had Colton. Like Tessa, Colton began experiencing seizures shortly after birth, but other than Tessa, there was no family history of a seizure disorder. Tessa and Colton were among the first in the world to be diagnosed with SLC13A5 Epilepsy.



Pictured: Tessa.
Photo courtesy of
the Nye Family

Kim and her husband are both carriers of SLC13A5 mutations, but two copies of the mutated gene must be inherited in order for a baby to have this type of genetic epilepsy. Such was the case for Tessa and Colton. In 2015, the family launched their foundation to fund research to better understand SLC13A5 Epilepsy and to accelerate the development of treatments and cures.



Pictured: Colton
Photo courtesy of
the Nye Family



Pictured: Kim (middle) with Colton and Tessa, Photo courtesy of the Nye Family

Thanks to the efforts of the Tess Research Foundation, more than 100 people have been diagnosed with SLC13A5 Epilepsy to date. Affected children have varying seizure burdens, but all of them have developmental delays that impact their education. While Tessa experienced hundreds of seizures a day and was severely affected, Colton's seizures are well-controlled by medications. Both Tessa and Colton were part of special education programs and had Individualized Education Plans (IEP) that help them work on their speech, as well as physical and occupational therapy. Colton also receives equine therapy to address his mobility issues. However, when COVID-19 hit, all of the Nye family's routines and support systems changed.

Having kids with special needs, or a seizure disorder, helped our family become resilient and flexible, two skills which were necessary during the uncertainty of the pandemic ...

Tessa and Colton were moved to distanced learning in March 2020. Colton was in distance learning for a few months and then went back to the classroom in person. He was shifted to a moderate-to-severe special education kindergarten classroom with a new group of teachers and an amended IEP. Colton experienced part of his kindergarten year as a mainstream student, where he befriended and learned from his classmates. But the pandemic changed his learning environment to an isolated classroom, with only four kids who also have special needs. For Colton, it has not been easy, but it is as good as it can be considering the pandemic.

Tessa, however, did not get to go back to in-person learning until April 2021. For more than a year, Tessa did not have access to in-person public education, peers, or any of the

specialists she previously had to support her learning. Kim and her family struggled to find help for their daughter during the pandemic because the high school's administration did not address their needs or provide tools for families with special needs children.

"The process was a challenge; Zoom school did not work for Tessa," said Kim. "We went from having a team of 12 people to having no one to help my daughter. There was more work put on the parents and caregivers. We suddenly were expected to be full-time aides and teachers in addition to working and parenting. My daughter regressed in her physical movements and her social behaviors. For Tessa, COVID-19 made her lose her community."

The silver lining of quarantining for her family was getting to spend more time together. Kim and her family continue to support Tessa and Colton and provide support to other affected families.

Kim advises other families to find a community with those who share a common diagnosis and epilepsy journey, because meeting and talking with other people can make the journey easier for parents, caregivers and their children.

"Having kids with special needs, or a seizure disorder, helped our family become resilient and flexible, two skills which were necessary during the uncertainty of the pandemic," said Kim. "We've also met some amazing people on this epilepsy journey, including other families, nonprofit leaders, researchers and clinicians."



For more information about TESS Research Foundation, please visit tessresearch.org



Photo courtesy of Yasa Pogarch

Yasa, Meet Epilepsy ... You Two Ought to Hate Each Other

By Yasa Pogarch

I have always had the generalized idea of what epilepsy is just as anyone else would. Television series vividly showing people dramatically gasping for breath while foaming at the mouth, writhing around in hospital beds uncontrollably, all while the heart monitor they are hooked up to beeps rapidly in an arrhythmic tune of impending catastrophic doom. Loved ones looking on with a look of panic and helpless horror on their confusion-struck faces. The reality of meeting epilepsy face-to-face was not too far from the truth. I had witnessed partial-focal seizures while volunteering at a local hospital, but my first experience witnessing a grand-mal tonic-clonic seizure was unnerving, to say the least.

Months before, I had begun working for Yuri, an awkward shy man who happened to run a construction crew. I wanted to gain hands-on experience framing residential houses. It was such an ordinary day on the site. My co-workers were downstairs working on building the deck and I was on the second floor. I called out to Yuri asking what size the headers were on the blueprint after I heard him give the guys some direction.

Our rock music was turned on to a loud, but tolerable volume. But I got no response from Yuri, even acknowledging that he had heard me. I walked halfway down the stairs, while the guys were dispersed zoning out on their own individual projects, joking aloud with each other. The strangest thing is that I know he heard me calling his name. I called out twice over the music, following a third time, with a slight hint of annoyance in my voice.

“Yur, you got the prints? How wide does he want the rough opening for his closet door?”

He turned around and looked at me in the blankest way possible when I called his name the first two times. Like someone who makes eye contact, hearing, but not really listening. Not really confused either. More like someone who is lost, but not very scared of being lost, if that makes any sense.

He turned back around facing the direction the guys were working. No big deal, except I was about to tell him he was being rude. I figured he had something else he was going to give the guys to do, or perhaps giving them something more important to do before we moved onto the next house. He proceeded to say nothing.

“Yur!” I called out again, louder this time and down a couple more steps, so he couldn’t possibility ignore me.

Another 180 turn, and blank stare, only to turn around again with no other vocal acknowledgement that I was speaking to him. That is when I knew something was up. We had only ever talked about it before, but as it was only in a past tense, there is nothing that could have possibly prepared me for what I realized I was just about to witness. I had an “ouh-oh” moment thinking, knowing, that something was about to hit the fan big time.

“Did he hear me?” I frantically called to my co-worker.

We made brief eye contact, but the poor fella merely shrugged his shoulders, and got back to whacking away at something with his hammer. He apparently was not observing our boss as closely as I was in that moment. I walked toward Yuri, and I guess my anxiety at that moment must have been airborne and contagious or something, because one by one, the guys followed, slowly forming a circle around Yuri like some dark cult while he was standing in front of a recently braced off wall.

After what seemed like one of the longest minutes of my life, I watched my friend and boss quickly bow forward in an awkward, sideways jerking fashion between two studs. The way his back contracted sideways made it look like he was trying to wedge himself between two studs with the path of most resistance. It looked as though every single muscle in his body had gone completely stiff, rudely ignoring the misfiring neurons that kept screaming signals for his muscles to remain calm. Like futilely trying to soothe a toddler you had just said “no” to. His jerking movements became more rapid and random, as every muscle in his body began to contract simultaneously.

We slowly lowered him to the floor, while mentally attempting to consistently remind our own brains about what we were witnessing for the sole sake of sanity. The seizures I had only ever heard him talk about as though it was a thing of his distant past, were now back and unfolding in a truly horrifying way. He hopelessly gasped for breath, over and over. His body was involuntarily convulsing more quickly now, as quickly as the individual muscles could manage. His eyes, wide open in panic and fear, completely unresponsive, as though visually seeing demons that the rest of us did not. His jaws were clenched together tightly, in a universal expression of debilitating kind of pain.

We began to see blood, slowly accumulating from the side of his tongue he was biting, and spill over into the saliva already heavily drooling from his mouth, all the while still gasping for breath frantically, as though he were violently choking on popcorn, only the air had disappeared from his lungs, and all he could manage was to move his mouth like a goldfish, eyes still popped out and body flopping around. The sounds he made were grunts, like someone’s body who fell flat on their back, knocking the wind out of them, repeatedly. Thankfully, one of us had the temporary soundness of mind to remove his tool belt, filled with nails, several freshly bladed knives, and a 20-ounce hammer.

“There ya go, buddy, that should help you not kill yourself for now.” I heard my co-worker CJ exasperatedly sigh something like “here we go again.”

Yuri has been living with epilepsy for 15 years which is a result of a traumatic head injury following a car accident in his early 20s. As I began to date this man who also happened to be my best friend, my curiosity about the mysteries behind the human brain

grew deeper. Yet, everything I searched for — whether it was comparing the side effects behind the common prescriptions or the effect that living with epilepsy has on relationships — was discouraging, to say the least.

The endless stories I keep reading about partners with epilepsy is no less unnerving. Most of the posts I read are written by people living with partners who have epilepsy and experience between one and three episodes a year. I have known Yuri for just over a year, and he just had his 12th seizure. Yes, in the last 365 days! Not complex partial seizures, but I am talking full-on grand mal, turning blue-in-the-face, tongue-biting, crazy-eyed, nightmare-inducing seizures.

I am not easily scared. But this new enemy of mine — this “condition” I am forced to wait for in my life — petrifies me. These seizures, the things that Yuri calls “side effects” are the stuff of nightmares. Yuri basically gets to check out of life during these episodes, and wake up feeling dazed, with no memory of what happened other than he got a quick head rush and fell asleep. Meanwhile, I am witnessing things that are unspeakably brutal on the human body. I am waiting and praying for him to wake up, just so he can go back to sleep and take a nap after all the seizures.

It is not his epilepsy. It is our epilepsy. It is a show run by us.

This thing is no longer just his condition, but our condition. It is not his epilepsy. It is our epilepsy. It is a show run by us. Only, I do not really run the show. I am like the quiet, seemingly insignificant coffee assistant who lives for the production, but takes no part in writing it. I just get to wait to be cued in and witness it unfold over time, dealing with the consequences.

Sometimes it feels as if I am alone. There is so much put on your shoulders because you feel like you always have to be the strong one. You have to be the one to drag your loved one out of the muddy darkness. You will feel like your needs are not being met because how are you supposed to allow weakness into your life when you are the strong one?

If you are a caregiver and feel a fraction of what I feel every day, get advice, support, and guidance. Lord knows, I can use all the help I can get.



GET SEIZURE FIRST AID CERTIFIED

Help us reach our goal of **certifying 15,000 people** by the end of June. The organization that registers and gets the most people certified will get a feature story in the next issue of Foundation Quarterly.

6/9/2021

3:00 p.m. ET

Seizure First Aid Certification with special emphasis on Men & Epilepsy in recognition of Men's Health Month

6/22/2021

4:00 p.m. ET

Seizure First Aid certification

7/8/2021

12:00 p.m. ET

Seizure First Aid Certification

7/20/2021

8:00 p.m. ET

Seizure First Aid Certification with a special emphasis on Minority Mental Health in recognition of National Minority Mental Health Month

8/5/2021

4:00 p.m. ET

Seizure First Aid Certification

8/17/2021

6:00 p.m. ET

Seizure First Aid Certification

Sign up at learn.epilepsy.com

For this Caregiver, Advocating for Her Son is Her Passion

Growing up as a young girl, Nikki Perry always thought she'd get married, have two kids and live in a house with a white picket fence. That dream, however, vanished when her son had his first seizure and she was unexpectedly immersed into the epilepsy world. Nikki's 12-year-old son, Max, has refractory focal epilepsy in his left temporal lobe and is also on the autism spectrum.

Max was 18 months old when he was first rushed to the emergency room because of a febrile seizure. The doctors performed an EEG which showed everything was normal, and the Perry family was told Max would grow out of it. But, in the next two years, he had two more febrile seizures. At the age of 4, Max would stare off and his face would get blotchy or pale, but the pediatrician didn't think there was anything wrong with him. While in the emergency room at the local children's hospital, Max had a seizure, was admitted, and an EEG confirmed an epilepsy diagnosis.

"When he was diagnosed, it hurt my soul, I feared for his future and what that would look like," said Nikki. "Your dreams and expectations go away. You start thinking that he is not going to be able to do things that other kids do, and you cannot do anything about it. Every seizure turns your insides black."

Following his diagnosis, Max had hundreds of seizures and was put on a variety of anti-seizure medications. He experienced many of the side effects that come with the medications, such as erratic behavior, self-harm, and change in taste and smell. At the age of 5, Max had his first brain surgery, but the surgery did nothing to control his seizures.

"His seizures actually became worse," said Nikki. "He began having them at night and could barely function." The family headed to New York City to see an epilepsy specialist, who suggested Max have another brain surgery. "While the second surgery did calm him down, he was still not seizure-free. The surgery got him back to baseline."



Pictured: Nikki (right) with Max. Photo courtesy of the Perry Family

When Max entered the first grade, his behavior was still erratic, so his family pulled him out of school and started intensive Applied Behavior Analysis therapy. Nikki resigned from her job so that she can be home monitoring the therapy and caring for Max.

Nikki is not just helping Max; she is also helping other families. Being an exercise science major and having attended law school, Nikki wanted to advocate for children. At first, she didn't know how she was going to do it. Her first opportunity came in 2015 when she spoke to the Nebraska Legislature and shared Max's story in support of cannabidiol (CBD) use for medical purposes. Nikki felt she needed to help bring this to Nebraska because families were moving out just to get access to CBD that could help their child.

Although, the Perry family tried CBD early on, and then later his doctor put Max on a medication cleared by the U.S. Food & Drug Administration, neither medical cannabis nor the CBD-derived treatment worked. Just like other medications he had tried, Max did not achieve full seizure control. But Nikki hasn't given up and continues to fight for her son and others with epilepsy.



Earlier this year, Nikki advocated for Legislative Bill 337, which was introduced by Nebraska State Sen. Mark Kolterman, and signed into law by Governor Pete Ricketts on March 31, 2021. The bill opposes step therapy, a health insurance practice known as “fail first” that restricts access to prescribed, life-saving treatment. For Nikki, this bill is particularly important because of her family’s own experience with step therapy. Max had tried as many as 12 medications before they found the right cocktail of medications that stabilize his seizures and does not cause him unbearable side effects.

Nikki has also contacted her elected officials in support of Seizure Safe Schools legislation. Nebraska recently introduced legislation, LB 639, which would improve the care of students with epilepsy and seizure disorders in schools. Nikki heard that there were some school board members who were in opposition of the bill and is urging legislators to help move it forward.



Photos courtesy of the Perry Family

As Max gets ready to enter middle school this fall, Nikki is starting a homeschool to help him get where he needs to be academically. She continues to raise awareness any chance she gets. She has volunteered to become a Seizure First Aid trainer, as well as an Epilepsy Awareness Ambassador and a Board Advocacy Committee lead for the Epilepsy Foundation in Nebraska. In addition, she has joined Facebook groups to connect with other families and offer support.

“As a caregiver, you get to a point in the journey where you embrace the diagnosis and just hang on to your child’s strengths to help grow all those strengths,” said Nikki. “My husband and I are now a well-oiled machine. We work through the negatives, relish on the positives, and do what we can to help Max and other families. I found this is my passion, it gets me more energized.”



Learn how to become an
Epilepsy Awareness Ambassador
at [epilepsy.com/Volunteer](https://www.epilepsy.com/Volunteer)

Behind the Curtain: An NFL Player and His Family's eJourney

An interview with NFL Baltimore Ravens Cornerback, Iman Marshall, about his brother's epilepsy journey.

FQ: How long has your brother lived with epilepsy?

IM: Maison has had epilepsy his entire life. His first seizure appeared two days after he was born. We were getting discharged from the hospital when we noticed Maison had become stiff, his eye was deviating to the right and his eyelid was fluttering. He was diagnosed with intractable epilepsy with complex partial seizures. After four years of countless anti-seizure medications, he is now solely on one medication.

FQ. How has Maison and your family been able to overcome challenges brought on by epilepsy?

IM: Maison has overcome many obstacles at the tender age of 8, despite having global developmental delay and cerebral palsy because of early-onset seizures. Some of the challenges include his inability to communicate and do common things that we take for granted, such as eating. Together with his wonderful mother, Alise, who works in the hospital as a nurse, Grandma Gwen, and the help of other family members, we have

created a loving and caring environment for him to grow.

FQ: As a family member of someone living with epilepsy, what would you like others to know about going through this journey with your brother?

IM: It is a journey that you should not be sad about. You should embrace and look at this as an opportunity to bring awareness to those who do not understand what is going on. Our perception of any given situation shapes our reality, so look at this as a new way to be a better, more caring, and loving person.

FQ: You are a great advocate for your brother. What are some things you are doing to help him along in this journey?

IM: I am using my platform to spread awareness as well as being as supportive as I can be when called on. My father and my brother's mother have done an amazing job providing a loving and caring environment that's best suitable for him.



Photo courtesy of Iman Marshall

FQ: What would you tell others who may be struggling with a sibling or a family member living with epilepsy?

IM: I would like to tell them that they are not alone in this process. I know at given times we feel like we are dealing with this all by ourselves, but there is support for people who may need help to see this through, not just for now, but for a lifetime. You can create an extension of family and friends who can help you, either through situations that you are dealing with, or situations you are placed in. Family is not just blood-related.

FQ: What does the kind of impact you could have leveraging your voice and platform as a football player mean to you?

IM: It means a lot to me because allowing people to see behind the curtain of our lives, no matter how high we go in our endeavors, shows everyone we are human. By using my public platform, as well as other platforms when given the chance, I can let people know we are in it together. If that means showing up to epilepsy-related events, I'm all for it. The more attention we bring to this topic, the more importance and impact it can have in helping bring solutions for future generations.

FQ: Anything else you would like to share?

IM: It is important for people to know what to do when someone is having a seizure; acting fast can make a difference in the life of a person experiencing a seizure. I encourage everyone to get Seizure First Aid certified by taking the free trainings offered by the Epilepsy Foundation. Visit [learn.epilepsy.com](https://www.epilepsy.com/learn) for more information.



Top: Maison and his mom. Bottom: Maison
Photos courtesy of Iman Marshall

A vibrant banner for the 'Summer Relay Stream for Epilepsy' event. The background features a sunset with palm trees and a large sun. The text 'Summer RELAY STREAM FOR EPILEPSY' is prominently displayed in a colorful, stylized font. Below it, the dates 'JULY 15 - JULY 18' are shown in a teal box. At the bottom, a call to action reads: 'Visit [epilepsy.com/StreamforEpilepsy](https://www.epilepsy.com/StreamforEpilepsy) for more info'.

IN YOUR COMMUNITY

Epilepsy Foundation Central & South Texas Awarded \$330,000 in Grants

Epilepsy Foundation Central & South Texas (EFCST) was able to endure and rapidly respond to the financial crisis brought on by the COVID-19 pandemic by redirecting their efforts to grant writing. As a result, EFCST received more than \$200,000 in COVID relief funds and another \$130,000 for general operations that were immediately applied to all 79 counties served by EFCST. In addition, EFCST submitted its first ever application for a grant from the Centers for Disease Control & Prevention to expand services to the entire state of Texas.

In addition to grant writing, EFCST hosted a virtual conference — Epilepsy Training for Behavioral Health Professionals— comprised of a highly diverse and accomplished panel of speakers and participation from more than 100 attendees internationally, as well as a Young Adults Retreat in March which even included the participation of Torres, a service dog who also has epilepsy. Central Texas Manager, Mary Saldivar, conducted the Epilepsy Foundation’s first-ever Seizure Recognition & First Aid Certification Training in Spanish. EFCST is proud that their resiliency got them through the worst year ever imagined and thrilled to continue providing services to the epilepsy community in Texas.



Young adults with epilepsy from across EFCST’s service area attended the first EFCST Young Adult Retreat in March 2021. Photo courtesy: Epilepsy Foundation Central & South Texas

Epilepsy Foundation of San Diego’s Annual Gala Raises \$192,000

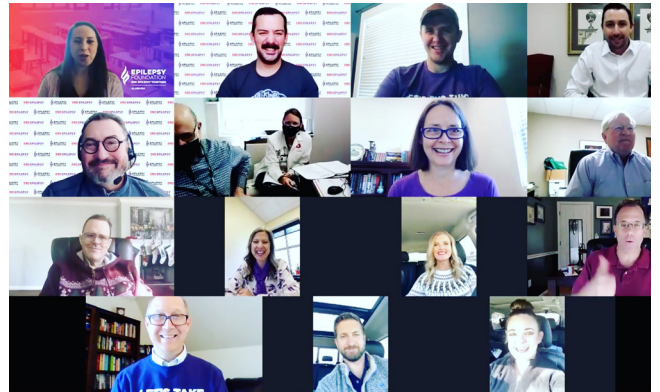
The Epilepsy Foundation of San Diego County reimagined the 27-year tradition of the Gingerbread City Gala into a family-oriented and socially distanced Gingerbread City Drive-Through event this past December. The multi-generational affair raised \$192,000 to support free programs and services offered to the 50,000 people in San Diego living with epilepsy. More than 350 cars and 1,000 attendees got into the holiday spirit as they experienced some of the most unique, fun and fanciful gingerbread houses, celebrating one of San Diego’s beloved holiday traditions in a unique format. Family-friendly entertainment livened up the experience including performances from the local Nutcracker ballet, a magician, and the Grinch who delighted attendees along the route. Sponsors and high-level ticket holders were treated to a VIP experience including a take-home wine and cheese platter and pictures with Santa. The event highlighted the theme “Holidays Around the World,” featuring gingerbread structures that celebrated various cultures and holiday traditions from around the globe. The Epilepsy Foundation of San Diego was determined to keep the magic of Gingerbread City alive.



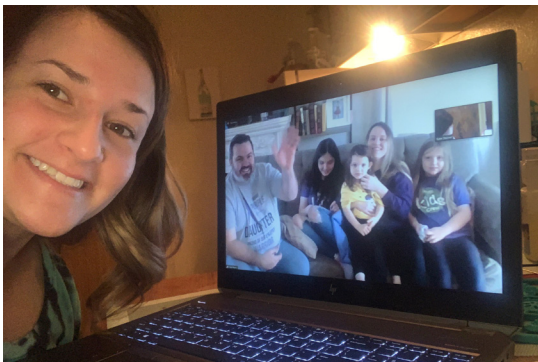
Photo courtesy: Epilepsy Foundation San Diego

Epilepsy Foundation Alabama Celebrates 50th Anniversary

Epilepsy Foundation Alabama celebrated its 50th anniversary this past January 26 with a livestreamed virtual birthday party that raised close to \$30,000. The date was chosen to represent the 1 in 26 people that will develop epilepsy at some point in their lives. The livestreamed focused on cherishing the nonprofit's history in the state, celebrating the milestone anniversary, and highlighting current work the chapter is doing to walk alongside those in Alabama going through their epilepsy journeys.



Epilepsy Foundation Kids Crew Member Featured in Mississippi Local TV

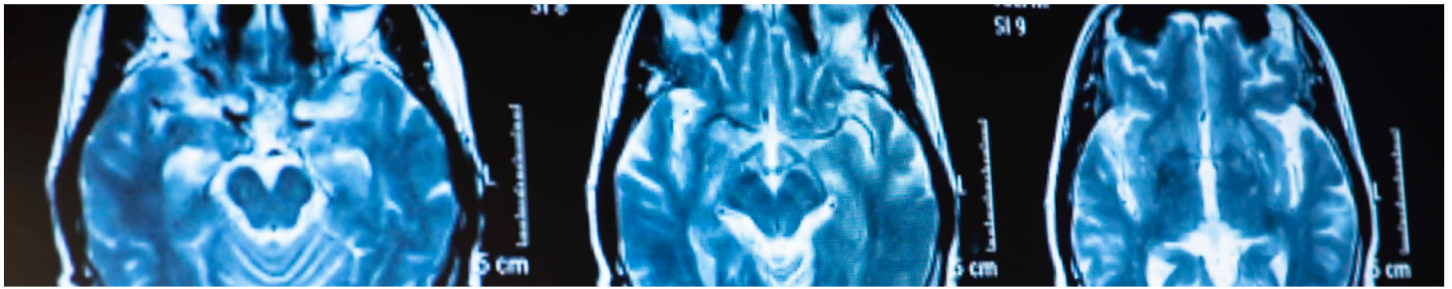


To celebrate International Epilepsy Day on February 8, WJTV-TV (CBS Crystal Springs affiliate) featured Kids Crew World Changer Claire Pecot. Claire is from Crystal Springs and has been wrestling with epilepsy for eight years. While it's been an uphill battle, she has used her struggles to empower herself and other children to join her in the fight. She worked hard to earn every Kids Crew pin in 2020, which she accomplished, making her the first and only Kids Crew "2020 World Changer" from Mississippi. But, that's not all she has accomplished. Claire recently had an EEG which did not show any more signs of epilepsy; she is now working with her medical team to ween off her anti-seizure medication.

Epilepsy Foundation in Louisiana Launches Community Engagement Board

The Epilepsy Foundation recently launched a Community Engagement Board in Louisiana. Board members include caregivers of those with epilepsy, physicians from LSU, people living with epilepsy, and those that work in public policy. The board in Louisiana is excited to begin working with the Epilepsy Foundation to spread awareness of seizure first aid certification, other education programs, and advocacy initiatives.





Seizure Forecasting Systems Enter Testing Phase

More than 65 million people around the world live with epilepsy, and 30 to 40 percent of people with epilepsy are not able to control their seizures with available treatments. For many, the constant fear of when a seizure will strike and the risk of injury and death because they cannot get to safety, greatly diminish their quality of life. Digital health tools and technologies, such as seizure forecasting, are greatly positioned to become an ongoing part of therapeutic treatment, leading to more patient control and freedom.

In 2018, the Epilepsy Foundation awarded a \$3M grant to an international team of scientists to evaluate biosensors that can track an individual's physiology, behavior, and environment to improve seizure prediction. Bringing together combined clinical, technical and device expertise, the team consisting of Seer Medical, the Mayo Clinic and King's College London (UK), formed the My Seizure Gauge Consortium to improve seizure forecasting. Seer Medical's role in the project is to deliver the data infrastructure to connect devices to stakeholders — researchers, physicians, and people with epilepsy — and be the global commercial delivery partner. To date, the My Seizure Gauge Consortium has published 13 peer-reviewed research papers on its findings surrounding long-term patterns of seizures measured from commercially available devices, such as the Seer App, wearables, and implantables.

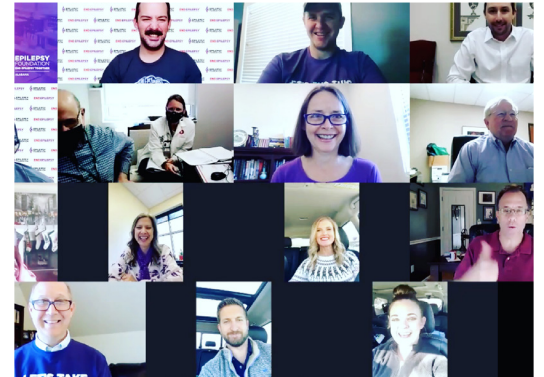
In addition, the systems that have been developed in the My Seizure Gauge project are now being leveraged across other research initiatives across the world. In particular, the Human Epilepsy Project, one of the world's largest long-term studies of epilepsy. As the final year of the project begins, the Seer Medical team is looking to build a community of ambassadors to be part of the trials for the seizure forecasting systems. If you, or anyone you know, are interested in helping shape seizure forecasting by becoming a Seizure Gauge Ambassador, please contact info@seermedical.com.

Have you Been Diagnosed with Developmental Epileptic Encephalopathies?

The Epilepsy Foundation introduced a new section on its website for Developmental Epileptic Encephalopathies (DEE), which refers to a group of severe epilepsies that are characterized by seizures that do not respond to anti-seizure medication and encephalopathy. Encephalopathy is a term used to describe significant developmental delay or even loss of developmental skills. DEEs are frequently caused by genetic variants, but can also have structural, metabolic, immune, and infectious underpinnings as well. Newborns through adults newly diagnosed with a DEE should promptly visit an epilepsy specialist to determine the underlying cause and identify the best path forward. Many precision medicine treatments targeting the seizure types and specific epilepsy genes are in development. If you are living with a rare, severe, or intractable epilepsy, check out this new content at <https://www.epilepsy.com/learn/developmental-and-epileptic-encephalopathy> and share it with others.

Get Seizure First Aid Certified & Help Save Lives

Since the Epilepsy Foundation launched its Seizure Recognition and First Aid Certification training in June 2020, the Foundation has trained and certified more than 12,000 people in seizure first aid. The certification program is focused on increasing the knowledge, skills and confidence in recognizing seizures and safely administering seizure first aid. Traditional first aid certification programs do not go into enough detail about epilepsy, how to recognize different types of seizures, or offer specific instructions for seizure first aid. The Seizure Recognition and First Aid Certification is specifically geared toward educating the public on the Epilepsy Foundation's approved procedures for recognizing seizures and responding safely to someone having a seizure. The training, which will soon be available in Spanish, is free for all general audiences and relevant professionals, such as law enforcement, first responders and childcare personnel. Participants who successfully complete the course will receive a two-year certification.



Become Seizure
First Aid Certified at
at learn.epilepsy.com

Former Ohio State Quarterback with Epilepsy Gets Drafted by Chicago Bears

Congratulations to Justin Fields on getting drafted by the Chicago Bears in the first round of the 2021 NFL Draft! According to news reports, Fields was diagnosed with epilepsy in the ninth grade and has since successfully managed the condition with medication. News of his diagnosis broke the week leading to the 2021 NFL Draft making headlines in the football community and creating speculation about how his diagnosis may affect his standings in the Draft. However, Fields himself has since come out to say that his condition “has had zero effect on football” and he’s “not gonna try to hide it”. Epilepsy is a neurological condition filled with silence and stigma. Field’s story is just another example of how high-profile influencers can help destigmatize it by leveraging their public platforms to talk about their journey. The Epilepsy Foundation hopes Fields engages in the cause now or in the future to help create awareness.

Teens Speak Up! & Public Policy Institute

During the Epilepsy Foundation’s 2021 Teens Speak Up! & Public Policy Institute, more than 160 advocates representing 38 states, including 54 teen representatives and ambassadors living with the epilepsies received advocacy training and held more than 150 virtual meetings with congressional offices March 22-26. Advocates shared their experiences of living with epilepsy and asked their members of Congress to provide \$13 million for the CDC’s Epilepsy program, as well as to ensure safe and legal access to medical cannabis and cannabidiol (CBD) and to promote research in order to better understand its potential benefits and risks through passage of legislation such as the Marijuana Research Expansion Act (S. 253). In addition, the Foundation awarded the inaugural Tony Coelho Impact Award to Representative Ed Perlmutter (CO-7) for his leadership in Congress including helping secure a nearly \$4 million increase for the Veterans Affairs Epilepsy Centers of Excellence in FY 2021. The Sara Stubblefield Advocacy Award was presented to Shari Dudo of Troup, Texas for her instrumental role in passing Sam’s Law in Texas, part of the Foundation’s Seizure Safe Schools initiative, as well as her work to include seizure education to the health curriculum for more than 4 million students in the state.

New Epilepsy Digital Experience Navigator Aims to Improve Outcomes



EDEN

epilepsy digital
experience navigator

powered by EPILEPSY FOUNDATION

The Epilepsy Foundation recently announced a collaboration with Eisai Inc. to develop a new platform — the Epilepsy Digital Experience Navigator (EDEN) — designed to empower people with epilepsy, their caregivers, and clinicians to use data to better understand and improve the epilepsy journey. EDEN will enable people with epilepsy to get connected to care, resources, and information tailored to their experience. EDEN will aggregate and analyze medical records, responses to surveys and data from connected devices to provide real-world insights for clinical research on new therapies and deliver new innovative tools and resources to the epilepsy community. EDEN will be powered by Embleema’s innovative technology platform which captures clinical and real-world patient-driven data and continuously delivers insights to multiple care and research stakeholders. The insights captured in EDEN may, in turn, help clinicians and researchers better interpret data to improve epilepsy outcomes. The Epilepsy Foundation plans to have EDEN up and running by Fall 2021.

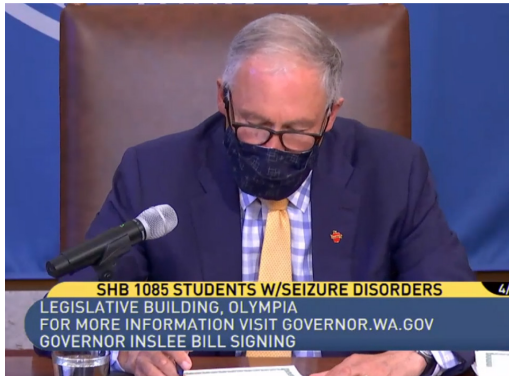
AI-Driven Digital Health Solution to Assist Clinicians in Developing Personalized Care for People with Epilepsy



Eysz is developing an AI-based software solution that analyzes passive eye-movements from compatible eye-tracking systems to assist clinicians in understanding their patient’s seizure burden and neurocognitive side effects, enabling them to create a more personalized care plan. The company’s goal is to help patients with epilepsy bridge the communication gap with their doctors by supplementing patient-reported data with objective remote monitoring data to improve outcomes and quality of life. In 2019, Eysz was awarded \$150,000 as part of the Epilepsy Foundation’s 2019 Shark Tank competition to develop and deploy 100 eye-tracking wearables to refine its patented seizure-detection algorithm. Since, the company has completed a proof-of-concept study and launched a multi-center clinical study. Eysz recently begun an offering under Regulation Crowdfunding (Reg. CF) to allow everyone, accredited and non-accredited investors, the opportunity to invest in the further development of Eysz’s Epilepsy Management Platform. The Reg CF offering will provide Eysz with the means to advance the technology toward regulatory clearance and commercialization.

For more information, visit <https://biovergeportal.com/startups/30-eysz-inc>.

Three More States Pass Seizure Safe Schools Legislation



Virginia, Washington State and Oklahoma have enacted Seizure Safe Schools legislation, bringing the total to 8 states! The Epilepsy Foundation leads the nationwide initiative to pass this bill in every state. The model bill requires the following: school personnel to be trained on seizure recognition and seizure first aid; administration of FDA-approved treatments in the school setting; every student with epilepsy to have a Seizure Action Plan on file; and education about epilepsy and seizure first aid for students. In late February, the Virginia legislature passed the Jamie and Brie Strong Act (SB 1322) and the bill became law in late March. In early April, Washington State passed HB 1085. Oklahoma passed SB 128 on April 20 and the Governor signed it into law on April 26. Kentucky, Indiana, Texas, Illinois, and New Jersey had already enacted laws. Seizure Safe Schools bills have also been introduced in the 2021 legislative session in the following state: Alabama, Arizona, Colorado, Iowa, Maryland, Michigan, Minnesota, Missouri, Nebraska, Rhode Island and South Carolina.

Six Protected Classes Victory

On March 16, the Centers for Medicare and Medicaid Services (CMS) announced rescission of a Six Protected Classes proposal that would have restricted access to epilepsy medications in Medicare. Under the proposal, which was released in January, Medicare plans could have chosen to no longer cover all or substantially all anti-seizure medications and instead, cover only one drug per therapeutic class. The Foundation's community responded with vigor, sending nearly 1,700 emails to the administration and the Foundation held several meetings with congressional offices and the administration asking for rescission. The administration's announcement specifically said that that stakeholder feedback was a large reason behind their decision.

Learn about Quality Improvement & the Epilepsy Learning Healthcare System

Would you like to get more familiar with what Improvement Science is and why [ELHS](#) is working to make it the basis for high-quality epilepsy care? An outstanding overview of how it was developed and is implemented in healthcare can be found [here](#). This is a 70-minute keynote lecture given by Dr. Donald Berwick, co-founder of the Institute for Healthcare Improvement. Consider watching it in installments during your trips to the beach/pool/park this summer! Contact the ELHS team anytime to learn more at elhs@efa.org



Learn about our
advocacy efforts at
at epilepsy.com/advocacy

CALENDAR OF EVENTS

See what's happening in this summer!

Camp Brainstorm

June 21-25, 2021, Camp Aranzazu, Rockport, Texas
Camp Brainstorm is a dream opportunity for youth with epilepsy, allowing them to enjoy all the freedoms of summer camp in a safe, medically monitored environment. For more information, call (210) 653-5353, email Camp@EFCST.org, or visit CampBrainstorm.com.

Camp Discovery Washington

Aug 15-18, 2021, Black Diamond Camps, Auburn, WA
Camp Discovery is a 4 day, 3 night camp for children and siblings impacted by epilepsy. Children with epilepsy can attend at no cost. One additional sibling can attend for free with additional siblings attending at \$150/child. Email Kevin Koppes for more information: kkoppes@efa.org.

Camp for Kids Raffle

May 21-July 2, 2021,
Closes at 8:00 PM
All proceeds raised from our raffle with help send youth with epilepsy to Camp Brainstorm, a weeklong summer camp specialized for children with epilepsy. Visit CampforKidsRaffle.com for more information.

Over the Edge

September 24-25, 2021, San Antonio, TX
Over the Edge is an intense and unique way for individuals and teams to fundraise for the opportunity to rappel from the top of a building!

For more information, call (210) 653-5353, email Events@EFCST.org, or visit EpilepsyOverTheEdge.com.

Seizure First Aid Certification Trainings

6/9/2021 3:00 p.m. ET
Seizure First Aid Certification with special emphasis on Men & Epilepsy in recognition of Men's Health Month

6/22/2021 4:00 p.m. ET
Seizure First Aid certification

7/8/2021 12:00 p.m. ET
Seizure First Aid Certification

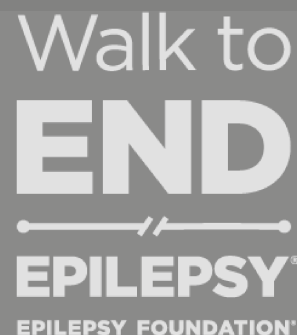
7/20/2021 8:00 p.m. ET
Seizure First Aid Certification with a special emphasis on Minority Mental Health in recognition of National Minority Mental Health Month

8/5/2021 4:00 p.m. ET
Seizure First Aid Certification

8/17/2021 6:00 p.m. ET
Seizure First Aid Certification

Stream for Epilepsy - Summer Relay Stream

July 15 -18
The inaugural Summer Relay Stream is here! Starting Thursday, July 15, streamers across the twitch-verse will be broadcasting a variety of content at every hour, until midnight on Sunday, July 18, to help raise awareness and fund life-saving programs and services for the epilepsy community. Register to [#StreamforEpilepsy](https://www.twitch.tv/streamforepilepsy) today, and aim to raise \$750 or more to earn our 2021 - 2022 prize season incentives! Register on [Tiltify](https://www.tiltify.com) or [Streamlabs Charity](https://www.streamlabs.com) on July 1.



Walk to
END
EPILEPSY®
EPILEPSY FOUNDATION®

Walk to END EPILEPSY® Series Virtual Closing Ceremony

June 5, 2021

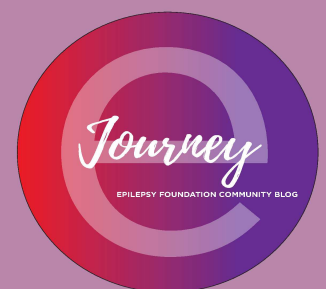
This June, the Epilepsy Foundation's Walk to END EPILEPSY® series will come to a close. Since January, family, and friends across the nation have hit the streets, trails, and treadmills to walk a mile-a-day or 100 a week to help the Epilepsy Foundation get to its 2.6-million-mile goal and collectively raise \$1.75M for the 1 in 26 people living with epilepsy. On June 5, Walk to END EPILEPSY participants, advocates, and partners will step up their strength and energy even further in a virtual closing ceremony featuring inspirational, engaging livestreams. The event will help connect participants with other likeminded epilepsy warriors throughout the country to help raise their voice and celebrate their accomplishments. Register for the closing ceremony at WalktoEndEpilepsy.org/Challenge



Your journey is your *power*.

Share your story to
increase awareness
and continue the
conversation about
epilepsy

Be inspired at
epilepsy.com/eJourney



Summer Safety for Your Loved Ones with Epilepsy



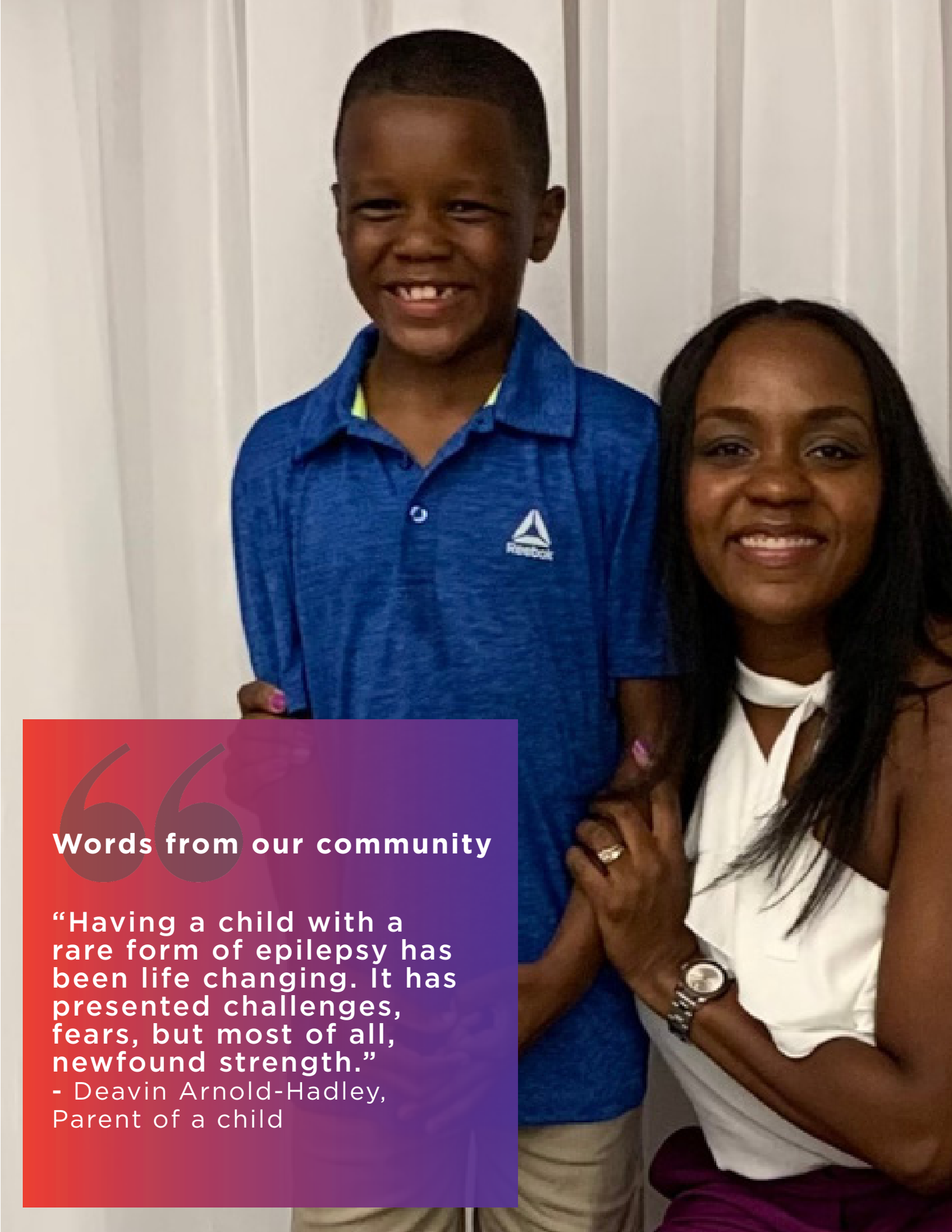
Summer is here, which means it's time to enjoy all the fun that comes with warmer weather. Hiking, biking, swimming, horseback riding, barbecues, boating, gardening, house projects, and many more activities are part of what makes this time of year so wonderful. It's important for those living with epilepsy to participate in these fun activities for their physical, mental, and social health, but it's also important to be mindful of safety.

Before engaging in any new activities, consult with your loved one's medical team to make sure they are appropriate for their individual situation. Second, make sure to let others know where and when they will be doing these activities. Even better, ask them to join in. And third, use common sense when choosing recreational activities. Low-risk activities should be appropriate for most people living with epilepsy; medium-risk activities are dependent on the person and their type of epilepsy; and high-risk activities should be avoided until the person is seizure-free for more than a year. In fact, some health care providers recommend completely avoiding high-risk activities.

Below are additional precautions to ensure their safety:

- Use a buddy system, wear a life jacket and have a lifeguard or strong swimmer nearby during water sports
- Teach those around you **Seizure First Aid**
- Sit back from flames and fire pits, and use fire guards
- Use the **buddy system** when swimming and climbing
- Use a **safety harness and helmet** when climbing
- Wear **safety gear** (goggles, helmets, guards, etc.) when using power tools, and use equipment with automatic stop switches

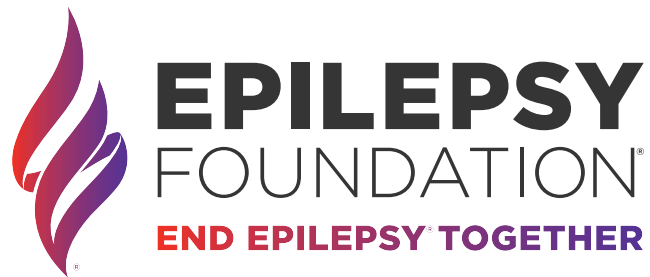
Click [here](#) to learn more about sports, exercise, and epilepsy. If seizures aren't under control, avoid swimming, pools, and open water; climbing to heights; and using power tools. If these can't be avoided, then make sure there is supervision.



“ Words from our community

“Having a child with a rare form of epilepsy has been life changing. It has presented challenges, fears, but most of all, newfound strength.”

- Deavin Arnold-Hadley,
Parent of a child



The mission of the Epilepsy Foundation
is to lead the fight to overcome
the challenges of living with epilepsy
and to accelerate therapies
to stop seizures, find cures, and save lives.

Learn more at epilepsy.com